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ABSTRACT

The paper addresses issues involved in the aging of persons disabled earlier through spinal dysfunction (post-polio and spinal cord injury) and mental retardation. Biological, psychological, and social aspects of aging are examined separately. In a discussion of longevity and physical health, causes of functional aging are considered. Psychological factors, such as depression, motivational problems, and cognitive problems are reviewed and the lack of research on this population cited. Social considerations, such as marriage stability, child rearing patterns, and living arrangements are discussed. Studies of physical health (including motor and respiratory problems) and psychological aspects (such as career satisfaction and affective disorders) are recommended, and service needs for this population are pointed out. (CL)

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# AGING AMONG THE DISABLED:

# A NEGLECTED AREA

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The paper presented at the American Psychological Association in August of 1983 by Bryan Kemp, Ph.D., entitled, "Patterns of Aging Among Physically Disabled People," has been re-titled, "Aging Among the Disabled: A Neglected Area."

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This paper explores aspects of aging among people who acquired a disability early in life and have lived with it for 30, 40, or even 50 years. It will examine biological, psychological, and social aspects of aging in this group.

To date, very little has been written about the problems of aging in this unique group, mostly because longevity has been a recent occurrence--principally since the Second World War. In this paper, two kinds of early life disabilities will be used as examples, spinal dysfunction (post-polio and spinal cord injury) and mental retardation.

Aging can be defined biologically, psychologically, and socially (Birren, 1964). Biological aging refers to the organism's ability to survive or its life expectancy. Cells, organ systems, and people age biologically at varying rates depending upon genetic, environmental, and lifestyle factors. Psychological aging refers to changes with age in the organism's adaptive capacities, such as learning, problem solving, the ability to cope with stressors. Social aging refers to a person's ability to fulfill social roles and expectations. People develop and age at different rates in each sphere. Biological maturity usually occurs before psychological maturity, which matures before maximum social abilities. Aging

proceeds in the reverse order--biologically, psychologically, and then socially (see Figure 1).

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Figure 1 goes here

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## Early Life Disabilities

There is a growing concern for the large and increasing number of persons who were disabled early in life and are now aging. The impetus for this interest comes from both the disabled population itself who express concern over the onset of what may be aging-type symptoms beginning in middle age (cf. Laurie, 1980) and from rehabilitationists who are seeing many middle aged and older persons return for assistance with a variety of problems.

The United States population contains about 240,000,000 people. Approximately 11 percent, or 26,000,000 are moderately or severely disabled. Of these, approximately 40 percent, or 10,5000,000 are over age 60. And of these ten and one-half million, about two million are people who were disabled at a young age (see Figure 2).

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The principal kinds of disabilities and their estimated numbers reaching age 55 today are:

Polio (n = 200,000)

Spinal cord injury (n = 200,000)

Arthritis (n = 400,000)

Mental retardation (n = 250,000)

Other neurological disorders (n = 150,000)

Other orthopedic disabilities (n = 150,000)

Mental illnesses (n = 250,000)

Sensory impairments (n = 300,000)

As a percentage of the disabled population, this group has grown since the early 1900s. This growth has been due to better surgeries, the reduction of infections, improved rehabilitation, and general public health improvements. It is a trend we will see more of in the future. Just as important, the chances of a person with an early life disability living to older age has increased. While exact studies of this do not exist, it can be estimated that the chances of survival to age 70 are now about 40 percent for a person disabled early in life.

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Figure 3 goes here

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This population is asking qustions about its own aging and is worried about many issues. Do disabled

people age more quickly? What are the physical risks? Are new symptoms an exacerbation of the original illness/injury? How are we doing as a group? Will I live as long?

Practitioners are asking similar questions: What new problems are emerging we didn't train people for? How are people coping with this? Are there more or different psychological problems? How should we follow and monitor people?

The remainder of this paper will examine biological, psychological, and social aging separately. First, however, it is important to note that what we call "aging" in the older person who was disabled early in life is a product of four major variables acting in concert. These are:

1. The biological effects of the disability over time, including the person's capacity to withstand biological stressors (e.g., chronic muscle strain, catheters, fractures, skin breakdowns, infections).

2. A lifetime in a particular lifestyle, including amount of activity, social participation, health consciousness, exercise, etc.

3. One's own psychological adjustment choices and patterns.

4. A lifetime of interaction with a nondisabled and sometimes "disabling" society.

What is observed in this population must be seen as the interaction of these four sets of variables.

## Biological Aging

This can be defined as the organism's longevity and capacity to withstand insult. In normal aging, certain cells and organ systems serve as "pacemakers" of aging. These are organ systems comprised of "post-mitotic" cells which no longer divide after maturity (about age 20) and whose longevity depends upon their integrity and ability for self-repair. These include cells of the central nervous system, cardiovascular system, immune system, and skeletal system. The "pacemaker" organs are integrative systems and thus in a position to greatly affect functioning of the entire organism if injured or diseased. As Figure 1 shows, biological functioning is maximal up until the age of reproduction and then slowly trails off.

Each organ system has built-in reserve capacity and people usually do not reach dysfunctional states until only 20-30 percent of capacity remains. For example, people can lose more than 50 percent of their kidney function and still survive easily. However, when a certain critical level is passed, the organism is highly

likely to become dysfunctional (ill). In addition to genetic factors and individual organ systems' ability for self-repair, lifestyle factors influence the rate of decline in organ systems and thus the rate of aging and the amount of reserve capacity remaining at any given age. The major variables of exercise, diet, smoking, alcohol intake, rest, stress, and body weight are the principal lifestyle contributors to the rate of aging. In order to understand the effects of aging, it is necessary to understand these lifestyle variables.

In older individuals, many systems are near critical levels. This is why an older person may often appear to be functioning very well and then a "minor" injury or illness, such as a broken hip, leads to a dramatic decline and even a sometimes fatal outcome. Thus, some people are "old" about age 60 and some people are still "young" at 85.

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Figure 4 goes here

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## Longevity and Physical Health

Longevity for disabled people has increased since World War II. Hohmann (1982) estimates that after the first 10 years following onset, longevity decreases by one percent per year for people with spinal cord

injuries. This extrapolates to a life expectancy of 60 to 70 years. This estimate may be a little low after the age of 65, however data are still needed on this point. Mentally retarded persons live longer now than at any time, but do not approach anywhere near normal levels for longevity (Benz & Halpern, 1982). Persons with early life polio appear closer to spinal cord injury statistics. Of course, the level of spinal involvement is important, with high levels being associated with lower longevity.

The physical risks and symptoms associated with early life disabilities are serious, common, and worrisome. Post-polio patients report mid-life onsets of respiratory problems, increased weakness and fatiguability, muscle function loss after exertion, joint pain, increased sleep requirements, and slower recovery times from acute illnesses. Many post-polio persons are using more respiratory assistance. Some wonder whether this represents further loss (death) of anterior horn cells (Laurie, 1980) or the results of excessive use of certain muscles spared by the original virus (Perry, 1983; Schneider, 1979; Vash, 1983). Many post-polio patients are experiencing pain on the opposite side from the original site of the attack. The excessive pain and joint problems observed are possibly due to one of

several causes. First, the polio left a lower ratio of nerve to muscle innervation, muscles that had less nerve control. Second, remaining muscle fibers have been overworked for many years and are showing signs of destruction. Third, mechanical problems, such as altered pelvic tilt have occurred.

People with spinal cord injuries have a litany of serious physical changes. The incidence of bladder cancer is twenty times normal (Hohmann, 1982). The mean glomerular filtration rate for the kidneys is in the lowest one percent for spinal injured males over age 70 compared to their normal controls (anonymous, 1981). Hypertension complicated by renal problems is high. There is twice or three times the incidence of degenerative arthritis, especially in the shoulders, neck and spine. Ulnar nerve atrophy and carpal tunnel syndromes are perhaps four times normal. Diabetes may be as high as three times normal (Murphy, 1982). Osteoporosis, and hence fractures, is much higher, especially in women. Infections are higher, as are skin problems. Physical strength is reduced. In one cursory survey (Hohmann, 1982), no one over the age of 60 with a spinal cord injury could execute a floor-to-chair transfer due to decreased physical strength.

In the mentally retarded group there are more infections than normal, a higher rate of sensory impairments (DeGiovanni, 1978), less joint mobility, and earlier gait disturbances.

Do these changes represent earlier aging? In a functional sense, yes. In a sense of intrinsic aging with accelerated cell death, probably not entirely.

The causes of this functional aging are probably multiple. First, disabled persons put greater strain on remaining, uninvolved systems or parts of systems. Arthritic joints develop because of excessive wear and tear that would have otherwise been spread over several joints. Bladder cancer develops because of repeated irritation to the urinary tract from catheterization.

Second, disabled persons have lifestyles similar to the nondisabled population, but in the presence of a disability this makes them more likely to "age" faster. Disabled persons probably have as high or higher levels of obesity; they use or misuse substances (like alcohol or medicines) at least as much and maybe more than the nondisabled population; disabled persons frequently lack strenuous physical exercise (which may be the most important factor as there is then not the opportunity to develop cardiac and respiratory reserve). Nutrition is not always closely watched and smoking is just as

frequent. These lifestyle factors interacting with the disability itself put the disabled person at the critical levels much sooner than nondisabled persons (see Figure 4). Diabetes is known, for example, to be highly influenced by improper diet and lack of exercise. When these are not properly monitored, for whatever reason, diabetes can develop and worsen.

There is no direct evidence that anterior horn cells die in post-polio, or that spinal lesions move higher. There may be fewer healthy neurons in mental retardation to begin with and if the rate of aging remains the same, it will lead to earlier aging in this group.

Capacities for reproduction over age are only decreased in cases where a lesion or other change has directly affected reproductive organs. Otherwise, near normal abilities are present (Deyoe, 1971).

Many disabled persons report a decrease in daily living abilities (Benz & Halpern, 1982; Hohman, 1982; Laurie, 1980). These include decreased abilities to look after self, more difficulty getting around the environment, greater reliance on electric wheelchairs and assistive devices, and sometimes a change in residence.

These changes, especially in the spinal dysfunction groups, are more common in men, more likely in persons

with an onset before age 10, and more likely in people who don't look after themselves.

## Psychological Factors

The six most common psychological problems found among a cross-section of disabled older (over 65) persons (not the early disabled) are (1) affective disorders, (2) cognitive impairments, (3) performance and motivational problems, (4) somatopsychic disturbances, (5) substance misuse, and (6) family problems (Kemp, 1983). The percentage of older patients with these problems is presented in Figure 5 based upon 121 cases. As can be seen, some problems occur among more than 60 percent of the patients. Ninety-eight percent of the sample had at least one problem.

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Figure 5 goes here

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There are no similar data for people disabled early in life. However, it is reasonable to assume that people disabled early in life have similar problems and no one is systematically addressing them. Certainly, both the early disabled and late disabled older groups have a far greater incidence of these problems than the nondisabled older population. For example, among the nondisabled elderly, the percentage with a depression is about 15

percent. Among the disabled, the rate is between 30 and 50 percent.

There is reason to believe that there might be some differences in the severity or nature of the psychological problems. The severely depressed younger disabled person probably does not survive to old age. They are prone to suicide--either directly or through self-neglect. A sense of existential ennui, demoralization, or a dysphoric mood may be more common. It appears (e.g., Hohmann, 1982) that many persons with spinal injuries develop problems in motivation to look after themselves after decades of living with a disability. It is not expressed as an outright giving up, but as "it would be alright with me if I didn't have to keep going through this." Sometimes the costs of going on are extremely high. Likewise, no evidence exists on the prevalence of cognitive problems because most studies have either not assessed this aspect or did not contain enough of the truly geriatric population to make statements (e.g., Deyoe, 1971; DiGiovanni, 1978). For the mentally retarded, because there is an increase in the prevalence of institutionalization, which itself affects intellectual performance, the older mentally retarded may <u>appear</u> more impaired intellectually than at an earlier age.

The prevalence of substance misuse among the disabled as a whole is higher than normal (Hohmann, 1982; Vash, 1982). This includes both over-the-counter "remedies" and medications. Attempts to treat somatic and psychic pain are high. Perhaps, though, the problem is less common in the older disabled because, again, the younger ones tend toward self-destruction.

Difficulty accepting a more dependent role in the disabled older person is especially hard. After overcoming the initial disability through hard work and often even being shamed into exertion and against dependency by staff of hospitals, accepting a dependent role is even harder.

Worries and outright fear about the future, about new illnesses, about the impact on others, about hospitalization, about unknown complications of the original disability and about financial status, future care, and future living situation are very common among the disabled who are now older (cf., Gorski, 1983).

## Social Aspects

### Employment

People who have had a disability for many years seem to have been employed for extended periods of time. An employment rate of about 50 to 60 percent is noted in the literature. Persons with spinal dysfunction continued

their educations (40 percent) and were employed at all levels from maintenance to professional. Mentally retarded persons were employed in settings ranging from sheltered employment to routine assembly tasks. Level of injury in spinal cord injured persons was not found to relate to employment status in a sample of 760 persons (El Ghatit & Hanson, 1979).

Early retirement is characteristic in this group. Many people retire in the middle 50s. This is usually the result of health problems, excessive hospitalizations, being grounded at home, or physical tiredness (Deyoe, 1972p; Hohmann, 1982). For the mentally retarded, who also display early retirement, the lack of retirement benefits is especially troublesome.

People who were married either before or after the disability are much more likely to be employed, although the direction of this relationship is unclear and may be due to a third variable.

Marriage and family

Marriage stability appears to be high. Of 121 persons disabled for more than 21 years, 73 percent were married at follow-up (El Ghatit & Hanson, 1976). Marriages that do not endure probably would not have endured anyway. Men are much more likely than women to get married and stay married after a disability. The

divorce rate among the early disabled is not higher than the norm for California as a whole (El Ghatit & Hanson, 1975).

Child rearing and outcomes of child rearing do not appear different than in the nondisabled population over the life span. Children turn out however they are going to and a disability in a parent seems to make little difference (Hohmann, 1962). Mentally retarded persons marry less frequently and have far fewer children. No reliable data on separation or divorce were found for this latter group.

One issue reported in the spinal cord injury literature is an early loss of libido, especially in the 50s. It is unclear whether this is due to prolonged lack of sensory orgasmic feedback, side effects of medicines, disinterest, or possibly borderline depression.

An especially important family issue is the death of the nondisabled family member. For persons with spinal dysfunction, the literature (cf., Benz & Halpern, 1982) suggests an especially devastating effect--far more than in the nondisabled or in the late-disabled group. This includes spouses for those who were married and parents for the non-married. These turn out to be the principal care givers and when this person dies it leaves both an emotional void and a practical problem. The likelihood

of death or illness for the disabled person following the death of the caretaker is likely high.

For those married persons, participation in community and family activities over the life span was high (Deyoe, 1972). In fact, at least among veterans, one gets the impression of a higher than usual degree of activity.

Living arrangements

For mentally retarded persons, older age brings a higher likelihood of institutionalization or of placement in a more restricted environment and less responsibility for self. Benz and Halpern (1982) report that in New York a statewide survey of public institutions found that while the percentage of persons under age 21 decreased over a 10-year span, the percentage of persons over age 65 increased. Seltzer and Seltzer (1978) found that among five types of domiciles (foster homes, family homes, group homes, semi-independent, and independent apartments) that foster homes were much more likely for older mentally retarded persons.

Death of a caretaker often leads to more restrictive housing for older mentally retarded persons. Since this is frequently an older relative, fewer options have been available. Moreover, when placed in more restrictive environments, residents were very overprotected and made dependent upon others (Benz & Halpern, 1982).

Most older persons with an early life spinal dysfunction reside at home. Of 219 spinal injured persons surveyed by Deyoe (1972), only 8 percent lived alone. The majority lived with family, either spouses, children, or siblings. However, very few persons over age 55 were included so it is possible that a greater percentage would be at risk of not living independently after age 65.

The threat of not being able to live independently after many years of hard-won independence is one of the bigger worries of this population.

Unmet needs

Research. The biggest need is for reliable data on this population of older persons with early life disabilities. We lack valid comparisons on many biological, psychological, and social variables with normal aged and late-life disabled elderly persons.

Many studies of physical health need to be conducted. These include studies of motor problems, nerve degeneration, cardiovascular function, respiratory problems, metabolic disorders, pharmacology, and infectious diseases.

Future psychological research priorities must include better data on the prevalence of depression and other

affective disorders, life satisfaction, family burden, career satisfaction, treatment of psychological problems, and the contribution of psychological problems to physical health.

Research designs must include more older persons as this population ages, and longitudinal studies.

Service. The biggest service needs appear to be (1) alerting existing public and private rehabilitation systems to the unmet needs of this group, (2) training rehabilitation staffs for life-long follow-up and treatment for disabled persons, (3) providing accurate information to disabled persons themselves to alleviate unnecessary concerns and to better plan future self-care, and (4) developing ongoing skill training programs directed at maintaining independent living after middle age.

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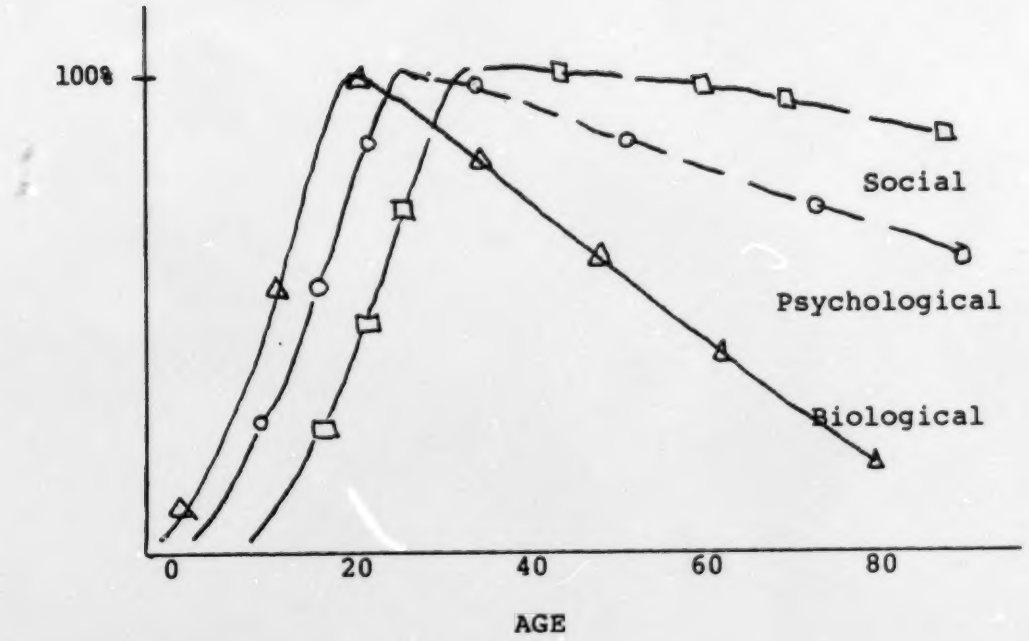


Figure 1. Theoretical rates of biological, psychological, and social aging.

Figure 2. Prevalence of older disabled persons.

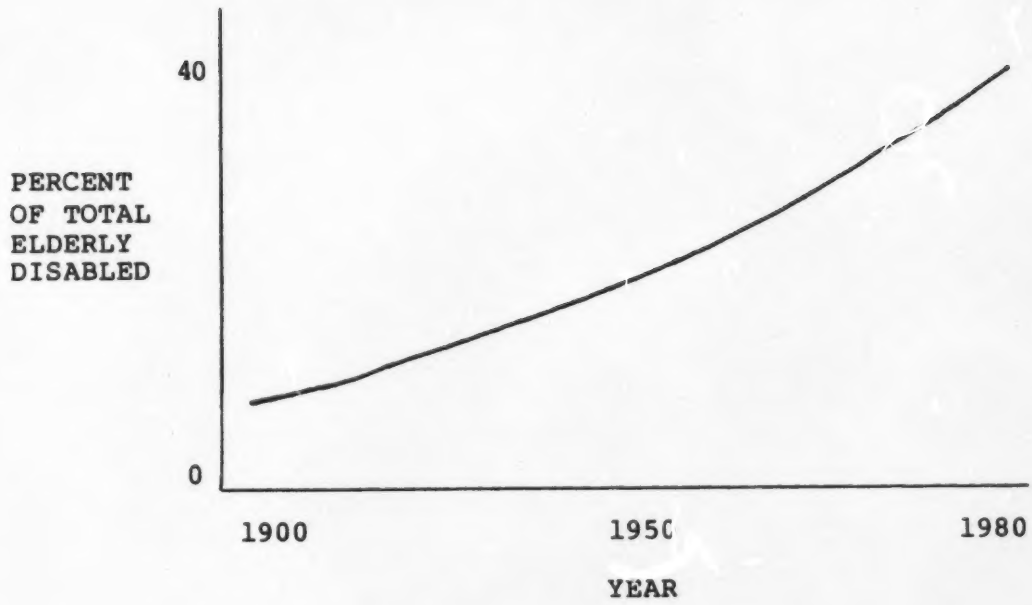


Figure 3. Rate of growth in early disabled living to old age.

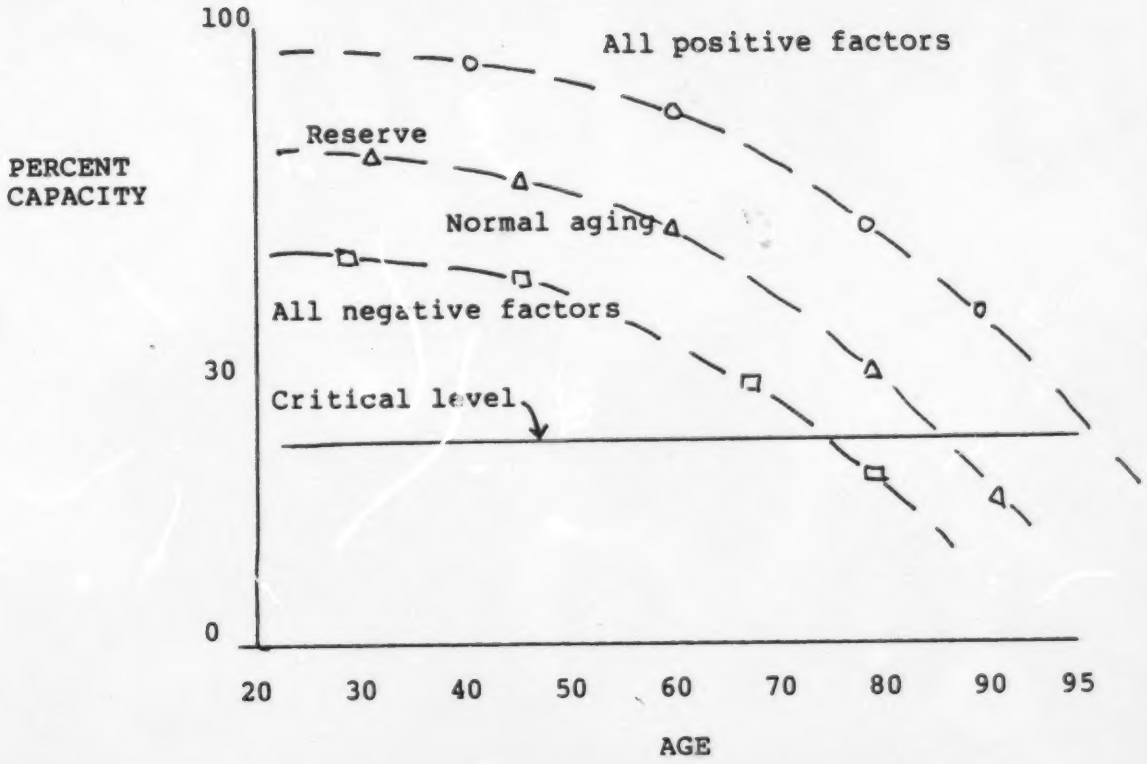


Figure 4. The influence of lifestyle factors on rate of aging.

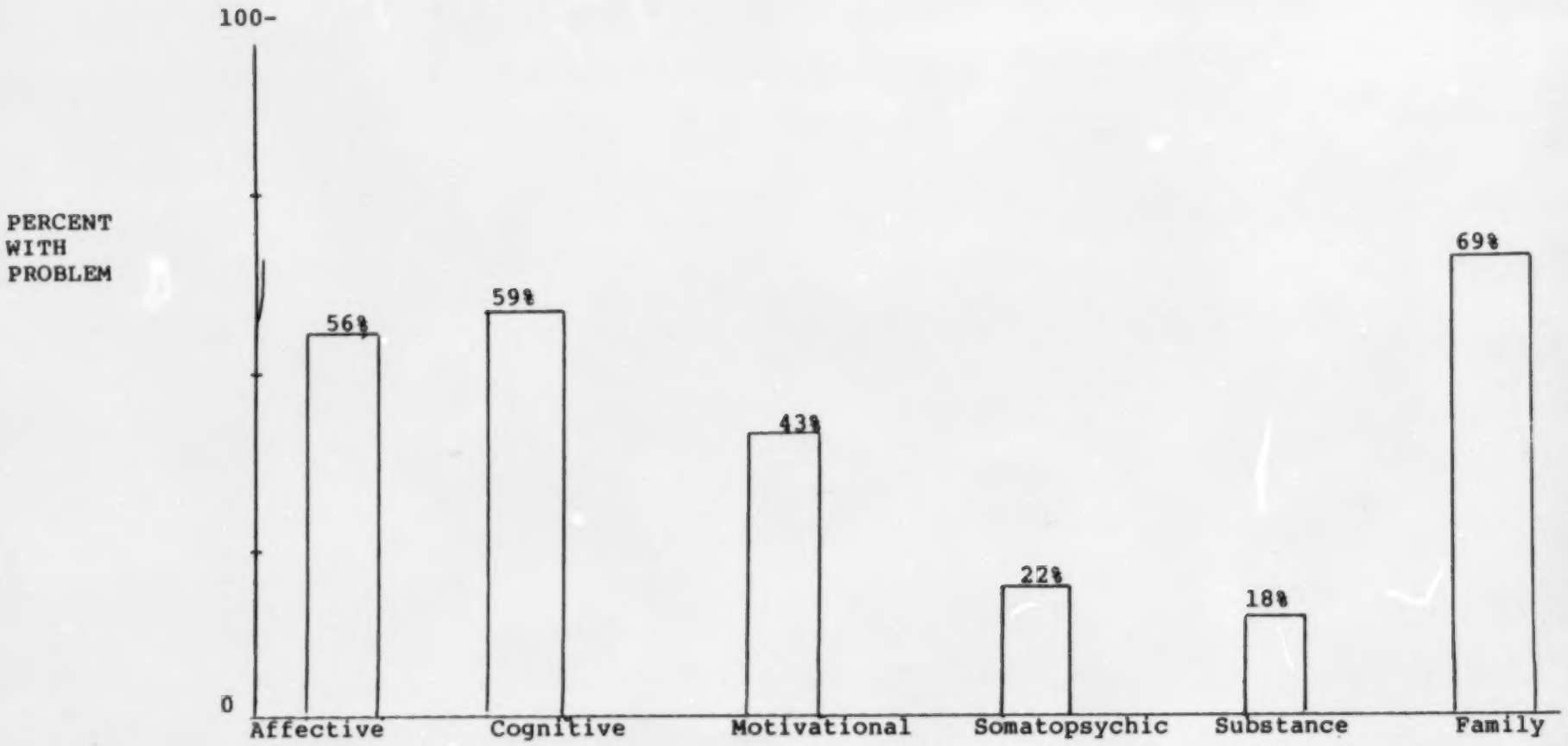


Figure 5. Psychological problems in a sample of disabled elderly persons.